Liminal Reproductive Experiences After Therapies for Hematological Malignancy


Abstract

In this article, we discuss the psychosocial health of young women related to fertility, pregnancy, and motherhood after therapies for hematological malignancies. We utilized a hermeneutical phenomenological approach to conduct in-depth interviews with 12 women who had previously received treatment for a hematological malignancy and had experienced uncertainty surrounding their ability to start or extend their biological family. Our presented findings are interpretations of the women’s own words as they articulated how they inhabited a liminal space. We concluded that although fertility and motherhood possibly might not be immediate concerns when they received a diagnosis of hematological malignancy, young women could subsequently experience ongoing issues and concerns related to reproductive uncertainty and motherhood capabilities, which have the potential to affect emotionally and psychosocially on their lives. These issues might possibly require longer-term support, counseling, and informational resources. We also discuss the strengths, limitations, and implications of the study.

Keywords: cancer, psychosocial aspects; coping and adaptation; fertility / infertility; hermeneutics; lived experience; mothers, mothering; phenomenology; pregnancy; reproduction

Advances in cancer detection and treatment have significantly improved the outlook for people who receive a diagnosis; however, treatment and management of the disease is not enough to ensure good longer-term quality of life (Redig, Brannigan, & Stryker, 2011; Schover, 2009). Complications of the disease and its related treatments are therefore becoming health issues that will continue to increase in importance as the number of survivors increases (Saxman, 2005). One complication that is now recognized is fertility impairment, which has a substantial adverse influence on various medical and quality of life domains of survivorship (Meneses, McNees, & Azuero, 2010; Redig et al., 2011; Stern & Seymour, 2006).
Although we acknowledge that some women face fertility challenges prior to a diagnosis of cancer, for others, the diagnosis itself might threaten their fertility. All cancers, either because of the disease itself or treatment side effects, have the potential to harm future fertility (Loscalzo & Clark, 2007). Biological motherhood after cancer is important, with the psychosocial literature confirming the strong desire to have children and the distress that infertility brings (Halliday & Boughton, 2011). Indeed, research has shown fertility to be a major issue for many patients (Duffy & Allen, 2009; Halliday, Boughton, & Kerridge, 2014; Redig et al., 2011; Schover, 2009; Tschudin & Bitzer, 2009; Zebrack et al., 2004), with concerns about fertility ranked second only to questions about mortality (Loscalzo & Clark, 2007).

Many women view motherhood as a source of identity, pride, and achievement and portray it as a transformational process that changes understanding of the body, the self, and relationships (Sevon, 2009; Walzer, 2007). The threat of infertility can therefore be devastating for a young woman. In a survey of young survivors of hematopoietic cell transplantation, 54% expressed elevated infertility concerns, especially if they did not have children. These concerns were persistent, even 10 years after treatment (Hammond, Abrams, & Syrjala, 2007). Fertility challenges can alter the reproductive experience, cause disruption to identity, relationships, everyday life, and future plans (Greil, Slauson-Blevin, & McQuillan, 2010; Halliday & Boughton, 2011; Halliday et al., 2014). In addition, infertility can also interfere with developmental tasks (Duffy & Allen, 2009; Zebrack, 2011) and thus compromise quality of life and general well-being (Canada & Schover, 2012; Gorman, Bailey, & Piece, 2012; Halliday et al., 2014; Penrose, Beatty, & Mattiske, 2012; Redshaw & Martin, 2009; Schover, 2005a, 2005b).

The purpose of our research was to investigate and explore the lived experiences of fertility, pregnancy, and motherhood for young women who had received treatment for hematological malignancies (HM) during their childbearing years and later wished to have a biological child. To this end, we conducted qualitative, in-depth interviews and analyzed the data using a hermeneutical phenomenological approach.

**Method**

Phenomenology is an appropriate approach in cases where little is known about a phenomenon and the aim is to delve into the lived experience of an event or condition to determine what it is really like (Willig, 2001). Hermeneutic phenomenology was selected because we aimed to approach the experiential horizon (Veseth, Binder, & Borg, 2012) of the participants while acknowledging that to understand the lived experience, we needed to interpret their dialogue to find the meaning (Heidegger, 1962; Kvale, 1996) and uncover and describe the essences of their experience as it was lived (van Manen, 1990). We believe that insights gained from exploring the lived experience using a hermeneutic phenomenological approach can contribute to knowledge and strengthen the case for an empathetic, nonjudgmental approach to fertility care and research in this particular context (Peddie & Van Teijlingen, 2005).

**Sampling**

The human research ethics committee at the University of Sydney, Australia, approved the study. We used several Internet sources to undertake purposive sampling, which involved four websites, one moderated email distribution list, and one online support group related to HM. Internet moderators/administrators posted information about the study and contact
details of the research team. Interested women sent email for more information and were forwarded a participant information sheet and consent form. Women who required extra information or who wished to participate and wanted to arrange for face-to-face or telephone interviews contacted us.

Participants
In all, recruitment totaled 12 Australian women aged between 25 and 39 years. All of the women were at least 1 year post their diagnosis of a HM. Time since diagnosis varied between 1 and 10 years. Of the 12 participants, 6 had been diagnosed with Hodgkin lymphoma (HL), 4 with chronic myeloid leukemia (CML), and 2 with acute lymphoblastic leukemia (ALL). Marital status varied, with seven women married, three single, and one divorced. In terms of motherhood status, five women already had children, but wished to extend their family; three were pregnant at the time of interview; one was actively seeking an egg donor; and three had not actively tried to become pregnant and were unsure of their fertility status at the time of interview.

Data Collection
The first author conducted the individual in-depth interviews, which were digitally recorded with each participant’s written consent and transcribed verbatim. Interviewing continued until no new insights into the phenomenon were revealed and data saturation (Marshall & Rossman, 2006[AQ8]) had been achieved. The opportunity to become familiar with and immersed in the data (Crist & Tanner, 2003) was afforded by repeatedly listening to the digital recordings at a reduced speed to enable transcription.

In keeping with an in-depth interview technique, the interviews were open ended and ranged from 40 to 90 minutes duration. Each woman was interviewed on a day and time that was convenient, and all participants were at home when the interview took place. We used face-to-face interviews when feasible, although on several occasions, because of the interstate locations of the participants and the financial constraints imposed by travel, telephone interviews were necessary. Throughout the research process, we employed several recommended procedures to ensure rigor, trustworthiness, and credibility including a clear and transparent audit trail, peer reviewing, and member checking (Creswell, 2007).

All participants were invited and made use of the opportunity to review the transcript from their interview to ensure validity. We assigned pseudonyms to protect participant’s identities in digital recordings and transcriptions, and we erased potential identifiers from quotes.

Analytical Approach
The essences of the phenomenon were uncovered using the six research activities outlined by van Manen (1990) including focusing on and investigating a phenomenon that interested us to uncover the lived experience. This allowed us to reflect on and describe the essential themes that characterized the phenomenon by maintaining a strong and oriented approach while balancing the research context by considering parts and whole.

To coincide with these research activities, the data were obtained through in-depth interviews with 12 women who had experiential knowledge of the phenomenon to allow us to deeply question and make sense of this aspect of cancer survivorship for young women. The women’s experiences were documented and their language, expressions, and emotions noted to explore the lived experiences in all its modalities and aspects (van Manen, 1990). The data were transcribed verbatim and analyzed with thoughtful reflexivity while remaining true to the women’s descriptions. This helped to identify and determine the
obscure and previously uncovered essential themes of the phenomenon. Being sidetracked and offering superficial analysis was avoided by keeping a focused stance in terms of the fundamental question we set out to explore, and we constantly read and questioned related literature, while allowing the research process to unfold free of predetermined rules. Each transcript was read line by line multiple times, and words or comments that appeared important in capturing the women’s experiences were highlighted and color-coded to de-contextualize the data (Sandelowski, 1993). In addition, notes were written in the margins of each transcription to facilitate reflection and aid in later stages of the analysis. This process was repeated several times because additional interviews were conducted. Color-coded sections of the transcripts were grouped together to allow commonalities of the experience to be revealed that helped phenomenological interpretation to occur (van Manen, 1990). To understand the essence of the experience, attributes of emerging themes were cross-checked and linked between participants and context. This led to several themes being merged or refined and the resulting essence of the experience being uncovered.

Findings
Consistent with other research documenting a cancer diagnosis as psychologically distressing (Tobin & Begley, 2008), and fraught with uncertainty (Liao, Chen, & Chen, 2008), the women reported that their diagnosis came as a major shock or they felt like they were thrown onto a rollercoaster or into a whirlwind. Their lives were immediately put on hold, plans and expectations for the future had to be immediately suspended and reexamined because they were thrown into the process of treatment and decision making; as one woman said, “Everything had to change.” From the moment of diagnosis, the women were situated in a liminal space outside the parameters of familiarity, in a place of uncertainty, vulnerability, and unpredictability.

Liminality interpreted here involved adaptation, adjustment, and development of a wide range of skills as the women negotiated the pathway to and through uncertain fertility, pregnancy, and motherhood. This adaptation and development occurred over time, with ebbs and flows of overt or subliminal liminality at differing time periods dependent on the specific reproductive phase in which each woman was uniquely situated. Therefore, what we present here attempts to capture something of the nature of this subjective, dynamic liminal experience, as portrayed through the lenses of the women who had lived it.

Uncertain Fertility as a Liminal State
Once treatment was completed, or effective means of controlling their disease established, the women entered the period relating to their passage back in to their former lives. This was signified by the realization that potential fertility impairment had changed them from what they previously were, to what they were now, without any clear indication of what they would become. For the majority, the obvious relief of survival was often tinged with sadness, anger, or regret once it became apparent that lifesaving treatment had come at a cost, potential impairment to their ability to achieve pregnancy and give birth to a biological child. This necessitated an alteration to predetermined life plans. “We suddenly went from deciding that we were probably likely to start trying for children soon to acknowledging that we may never do that.” One woman clearly articulated her turmoil:

Ever since I was little, I always had dolls and always played with kids and babies and stuff, and everything we had and went to and everything, so I just like, I know I was a person that has always wanted kids. I have never been a person who would wonder whether I would have kids or whatever cause it was always something that was going to happen or I was going to have.
They found themselves in the liminal situation of not knowing their status, believing they were stuck with no clear direction of who to see or where to go. This involved their often desperate and frustrating search for answers and a definitive answer concerning their reproductive ability. During this in-between time, the women’s lives were frequently dominated by their experiences of uncertainty, which developed as time passed “After probably about six months I started to get quite concerned about that, you know, I just didn’t have any sort of certainty or information about whether it might impact or was impacting on my own fertility.” Being situated in a liminal state was apparent in the way they described their situation, which was a constant source of frustration and anxiety as they tried to determine the likelihood of having a baby: “It’s all very up in the air and very uncertain cause I don’t know how this drug affects my fertility.”

In the absence of a clear pathway to help or any professional direction, there seemed to be nowhere or no one for them to go to talk to, there was a gap, and in light of this, the liminal experience was portrayed as a sense of being unable to move forward or being in limbo. Molly articulated how she was suspended between roles, in a sense, having been declassified as unconditionally fertile, yet not yet reclassified as fertile; she inhabited a liminal place filled with uncertainty:

I didn’t know what to ask and if I did ask, I still didn’t get the information so I just couldn’t learn anything. I couldn’t move forward with it. It was like I was stuck and I don’t think that is right. I think that there should be information provided.

As they learnt to incorporate their uncertain fertile status into their lives, they started to work through options to enable them to cope with their uncertainty and to progress through their liminal state as normally as possible. For example, for several of the women, uncertainty enabled them to remain positive, suspended in a liminal state of hope and optimism that they would one day conceive. Lynne said, “You know there is a small amount of hope, not a lot but you know they are coming out with treatment and what have you. They may come up with drug treatments that can be taken in pregnancy.” Others kept sight of positive things in their lives such as their existing children. “I always felt lucky that we had, at least we had had a child, and like you see people that obviously don’t have any children and can’t have any children” or focused on friendships and relationships and emphasized that they could be in worse situations.

**Pregnancy and Liminality**
Conceiving after HM meant entering a liminal space because they embarked on a transition through the process of pregnancy, characterized by uncertainty, anxiety, and a dichotomy of hope and fear. These women were transitioning over the threshold and becoming pregnant, which led them into a completely new experience of liminality. They had left behind the status of uncertain fertility and commenced the transitional state, from woman to mother, and entered the liminal space of high-risk pregnancy where the women negotiated various emotional, psychological, and social hurdles.

For the women who achieved pregnancy post diagnosis, a sense of relief was experienced, as well as conflicting emotions spanning positive and negative elements, such as feeling elated, excited, ecstatic, as well as anxious, worried, scared, and fearful, even though they had desired this moment often for a long time. Nonetheless, being situated in a liminal space meant experiencing the relief and joy of pregnancy and motherhood potential and, at the same time, being anxious and uncertain of the outcome because of their experiences of
cancer, the challenges they had traversed to get to this point, and the inherent concerns, uncertainties, and doubts they had for their future. They were pregnant, but still unsure of what the likely outcome would be.

Although actually conceiving had healed many uncertainties and fears, such as potential infertility, they still carried the scars of cancer. They carried the threat of hereditary genetic unknowns, of problems to their babies or to them because of the effects of treatments on their bodies, and the fear that their body would not cope and they might have a recurrence. Even though this was often unfounded, it was a real perception in these women’s experiences. Confirmation of pregnancy took away infertility uncertainty, but introduced a high-risk pregnancy and all the related unease and uncertainty:

I have got my twenty week scan coming up on Friday and I just feel like once I get to that point and find out that everything is ok I can relax a bit. You know I quite often say to my partner I just hope that everything is ok, because I have seen so much illness. I have been in hospital, so they have put me into a high-risk category.

This influenced their belief that there was still a long way to go until the baby was to be born and that nothing could be taken for granted. When Christine was asked what her main concerns were at this time, she replied, “I guess it was closure, that I was gonna have this baby and then we would move on. I just wanted the closure I guess, but I wasn’t entirely sure that the closure was gonna happen at all.”

These women, because of their cancer histories and the fear of recurrence, particularly during pregnancy, were attuned to changes in their bodies, because it became a focus of their attention as they undertook somatic vigilance for changes that could signify a return of their disease. This enhanced focus on their bodily symptoms diminished the easiness of their day-to-day lives. The women’s stories were scattered with comments such as “In the back of your mind it can change at any time.” Under their increasingly watchful eyes, physical symptoms associated with typical pregnancy, such as swollen ankles, aches, and pains took on new dimensions and became ominous threats to them and their unborn child. This was easily triggered and particularly likely around scans or routine checkups, which for the most part were extremely stressful and contributed to anxiety and distress situating them in a cycle of anxiety and then relief when a health-confirming result was received.

If it was necessary to stop treatment to conceive, not only were scans and testing anxiety provoking but also the uncertainty related to testing to determine molecular response. This facilitated an enhanced focus on their bodies and caused uncertainty and anxiety throughout their pregnancy:

I felt pretty anxious waiting for those results to come in each month, they would take about three weeks to a month to come back through, so we were always sort of a month behind sort of thing, you know before we knew where we stood.

They were unable to take anything for granted until they were actually holding the baby in their arms. “I really didn’t think I was gonna have a baby until she was like given to me, like physically there. Even at thirty-six weeks, you know, I still didn’t believe it.” This was a liminal state because although pregnant, they were doubtful or unsure of the outcome. They did not know whether they could actually achieve motherhood and thus the end could not be predicted with any certainty. In a way, they had left the pregnant state enjoyed by normal women, and instead entered a pregnant state of a cancer survivor, with all the related unknowns and uncertainties of the outcome, which continued until late into the
pregnancy. This was demonstrated clearly in the way they were reluctant to purchase baby things or prepare their homes:

I didn’t shop till twenty weeks cause I you know I was worried we might lose it or this that the other, and you know, I still hadn’t done very much in the way of preparing for the baby. We had ante natal classes at about thirty weeks and all these people were saying they had nurseries done and this that and the other they had bought all their stuff so we actually went out the next day and did a bit of that, so I think to some degree I was not letting myself get too excited in case something happened, or even at that sort of late stage, but at that point I decided that if they’d all decided that things were very likely to proceed positively then we should as well.

Motherhood: A Liminal Existence
Although five women had successfully conceived since diagnosis, only three women interviewed had actually experienced giving birth to a full-term baby since diagnosis. Giving birth for the women here meant completing the circle. It was a chance to move forward to a new start or a sense of being back where they would have been. Nevertheless, the liminal space of motherhood after cancer was constructed as an experience filled with uncertainty, with thoughts about the future mingled with thoughts about the present, both linked to their past experiences.

Motherhood for these women was perceived as different to the motherhood they identified with prior to being diagnosed and the motherhood they saw when comparing themselves with their peers, showing how mothers with a history of HM occupied a marginalized and liminal space. Like any woman, these women were consumed with the task of caring for their child(ren); however, they lived with a reality that saw them not fulfilling the normal mothering roles they expected:

God I wish that I knew that I could be around until I was a hundred and see them laugh and cry and do the first boyfriend thing and you know be there to support them in their struggles, but in reality that may or may not happen.

They felt cheated that the taken-for-granted-ness of being around to see the usual developmental tasks in their children’s lives—“Growing up, fall in love, get married and have their own babies. I just can’t imagine missing out on that.” This placed them in a different space to other typical mothers, who, although there are no guarantees, can generally expect to see all these things in their own children’s lives. Their paradigms were different and this made a difference to how they viewed themselves. They were situated in a liminal psychological space. The uncertainty of their futures through the threat of recurrence, or secondary malignancies, created disequilibrium and a sense of liminality made up of fear not only for their present well-being but also for the future they valued. They described the experience as “Like being in limbo all the time.” Jo stated, “I still get anxious and worried about it no matter when it is and I hope that goes away.” They feared recurrence not only for themselves but also for the impact it could have had on their children. One mother cried as she said:

The other week when I was having a breast lump investigated my first thought and the first thing I said to the fellow doing the biopsy was I just don’t think my son can go through it again. I don’t know, I think it would scar him really badly if I was sick again.
Because of living with their futures in doubt, the women had a shift in perspective involving a deeper appreciation for valued things in life, and a sense of making the most of each day, and making sure things were in order. In one mother’s words “It all comes back down to preparing everything for the kids,” and this appeared true for all the mothers who participated. One crucial part of preparation appeared to be the emphasis of future security for their children. This involved making sure that financial provision was in place for them, that they were fully informed or aware, through either conversations or written letters, of any future issues that could affect them. They also emphasized how things could happen at any time that could change life’s direction. These activities seemed to allow them to acquire a perception of organization and control in an uncertain environment.

Making sure photo albums were in order and that they both had something that was up to their stage of life already, I didn’t actually write them any notes, I think I thought about writing them letters and things I had hoped for them.

Another ritual involved an emphasis on memory making, compensating for potential time lost by “cramming everything in,” which spanned many different activities that were continuously reviewed and included spending quality time with their children, having fun, and being spontaneous, articulated as “some sort of stupid deep mission.” Jo said, “You start thinking about all those things and how you provide all those memories for them that you hope they would want in the long term.”

Discussion

Like other young women who receive a diagnosis of cancer, having previously taken life for granted in prospect of a normal future, these women experienced the struggle of being in between two worlds in their lives—one maintaining what used to be ordinary before the illness and the other facing a life with an illness history (Ohlen & Holm, 2006). The previous taken-for-granted-ness (Little, Jordens, & Paul, 1998) and assumptions they had of their future reproductive lives were replaced by uncertainty and confusion. Although not officially classified as infertile, confirmation about whether they were able to have a(nother) child had not been received. Thus, they were located in a temporally, medically, and socially undefined liminal state hovering between reproductive capacity and incapacity (Sandelowski & de Lacey, 2002). This period, between self-awareness of a potential problem and receiving confirmation of their status, can be viewed as liminal or boundary straddling (Jackson, 2005).

Liminality denotes a ritual of transition or rite of passage between one social status and another (Van Gennep, 1960), for example, between adolescence and adulthood (Warner & Gabe, 2004). Van Gennep (1960) claimed that, typically, people are classified into one distinct category, for example, man or woman, fertile or infertile, healthy or sick; yet, there are cases in which a person’s state is liminal—neither here nor there—their identity is somewhat ambiguous and undefined because of a clear or definite lack of status (Rassin, Lowenthal, & Silner, 2005). Turner (1996) later referred to this as betwixt and between.

A liminal space can be physical, psychological, or conceptual and helps manage periods of disruption and ambiguity when the social world of the individual is subjected to change and volatility (Allen, 2007). Liminality can complicate our effort to construct identity—we do not know what we are, how we fit, or whether we belong. It has been used as a heuristic to understand the effect of ambiguous and uncertain states in a variety of health-related contexts, including cancer (Corbeil, Laizer, & Hunter, 2009; Little et al., 1998; Navon & Morag, 2004). According to Harrow, Wells, and Barbour (2008), the liminal experience
separates the person from what they previously knew and understood about their lives and signifies a period of uncertainty during which they are dependent on others for guidance and instruction. This seemed consistent with the women’s reports of desperately searching for meaning in a new complex and unfamiliar world. Although it is acknowledged that there is an element of liminality surrounding every woman’s ability to predict reproductive success, it usually exists as a background to the normal progression of conception, pregnancy, childbirth, and mothering. For the women here, liminality was experienced persistently in an apparently exaggerated form. Liminality was multi-faceted and several factors influenced the experience, the most important being the reproductive phase (e.g., childless, pregnant, already a mother) in which each was situated when diagnosis occurred, as well as the amount of information and social and professional support received.

Young (1984) stated that pregnancy, as an existence, is a unique temporality or process of growth and the woman can experience herself as split between past and future. Concerns throughout pregnancy have commonly been reported as significant for young cancer survivors (Schover, 2005b; Zebrack et al., 2004), and after all the difficulties and uncertainties experienced to get to this point, they appeared embedded in these women. The experiences of pregnant women in this study mirrored those of previous research (Galloway, 1976). Women with high-risk pregnancy are usually in a vulnerable emotional position because of fears, anxieties, and uncertainty concerning whether or not their baby would be normal, what implications the pregnancy and birth would have for their own health, and how their relationships could possibly be affected (Arias, Daftary, & Bhide, 2012). Thus, high-risk pregnancy requires specialized, tailored care to deal with specific needs, anxieties, uncertainties, and stresses that characterize these circumstances (Arias et al., 2012).

For these women, a diagnosis of cancer added another dimension to the usual challenges of motherhood (Campbell-Enns & Woodgate, 2013; Semple & McCance, 2010) and disrupted their identity as a mother (Kayser & Sormanti, 2002). Similarly, mothers who had breast cancer described how they encountered an out-of-the-ordinary experience and struggled with being in between two worlds—one maintaining what used to be ordinary before the diagnosis and the other was facing motherhood with an illness (or illness history), which meant inevitable changes in identity (Ohlen & Holm, 2006). The liminal space they inhabited disrupted the normal course of events, including the need to reframe the mother role (Campbell-Enns & Woodgate, 2013; Semple & McCance, 2010).

Limitations
Annells (1996) claimed that there is no one true meaning produced by any interpretive study, but the meanings that are stated in the research findings must be logical and plausible within the study framework, and they must reflect the realities of the study participants. The findings reported here are grounded in the data provided by the women themselves, with their own words used to authenticate or verify any interpretations made. Thus, the findings reported here specifically relate to the 12 women interviewed and therefore might not apply to all other young women diagnosed and treated for HM. It is also worth noting that these women self-selected, and therefore might have had a personal interest in this issue because fertility was problematic for them, and therefore possibly could have sought avenues to share their experiences. Saying that, equally many of the identified concepts discussed here could be applicable to other young women, particularly those aged between 25 and 39 years who receive treatment for various other types of cancer during their childbearing years.
It is also important to stress that interviews only provide a snapshot of frozen time in highly changeable trajectories (Weiner & Dodd, 1993). Therefore, longitudinal studies are needed to follow women’s uncertainty as they progress through the reproductive trajectory, particularly those who are childless when diagnosed. In addition, expanding these findings by focusing on specific aspects of the reproductive experience would be beneficial in providing in-depth knowledge of the many nuances and intricacies inherent in different reproductive phases.

Recommendations and Implications for Clinical Practice
Like most cancers, treatment choices for HM have become much more effective, allowing those affected to look beyond their diagnosis and consider life post cancer. Therefore, this study is significant and relevant for an increasing number of young women who will undergo treatment for HM in young adulthood and who will survive and wish to have a (another) child. This study provides a new foundation of information, because there have been no formal qualitative studies in Australia, or indeed elsewhere, of what it is like to live with uncertainties surrounding fertility, pregnancy, and motherhood for young women after treatment for HM.

As Schover (2009) stated, controlling cancer might be vital, but it is not enough. When initially faced with a life-threatening diagnosis, issues regarding fertility, pregnancy, and motherhood might be of less focus; however, they remain a primary concern for women, particularly in the months and years after a diagnosis is received. Fertility and the ability to be a mother have been identified as core elements of quality of life in young women after HM (Halliday et al., 2014), and this research has demonstrated how, for the women who shared their experiences in this research, unanswered questions and a lack of specific, available information left them feeling unsupported. It has highlighted the need for, as well as the importance of, establishing clear pathways for the management of women who find themselves faced with a diagnosis of HM and who consequently face fertility, pregnancy, and motherhood challenges.

It would be naïve to assume that uncertainty about reproductive capabilities could be eliminated given their complex and multidimensional nature and the depth and breadth of its variability in this situation. Nonetheless, women’s questions and lack of certainty can be reduced by providing greater investment in managing this aspect of cancer care through thorough and comprehensive discussion of options, and suitable referrals to fertility specialists, alongside longer-term counseling with a qualified fertility counselor.

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